

Managing Post-Exertional Malaise (PEM) in ME/CFS

Helping patients manage PEM should be one of the first actions healthcare providers take. One of the best options to minimize or prevent PEM is to help patients learn to keep all energy expenditures, physical, cognitive and emotional, within limits that can be tolerated by planning when and how to use their limited energy. This approach is known as pacing. Minimizing PEM can lead to stabilization or improvements in pain, sleep, fatigue, cognition, and other symptoms. It can also prevent worsening of these symptoms. Activity pacing may improve quality of life considerably and even increase function.



Ask



Review



Brainstorm

- **Ask patients to keep a daily diary** for 1-2 weeks of symptoms and the activities they engage in, including type, intensity, frequency, and duration. Such a diary can help recognize energy limits and the links between activities and episodes of PEM (e.g., walking a short distance one day and then experiencing PEM hours or days later).
- **Review the diary** with the patients and ask whether they see any patterns. For example, a patient may find reading for 30 minutes is fine but reading for an hour continuously leads to PEM. Thus, this patient's energy limit for reading is 30 minutes.
- **Brainstorm techniques with patients to adjust the activity** to avoid or minimize PEM. For example, patients could set a timer for 30 minutes to stop reading, switch to audiobooks occasionally, read during the time they have most energy, or schedule a time to rest after reading for 1 hour.

Best practice: prevent harm! In the past, patients have been advised to be more active without any precautions about PEM. However, studies have demonstrated a lowered anaerobic threshold in patients with ME/CFS, suggesting impaired aerobic energy metabolism. **Increased activity can thus be harmful if it leads to PEM.** For some patients, even activities of daily living can trigger PEM. Any recommendation for increased activity or movement should take into account the patient's energy limits (i.e., the "energy envelope") and must be specific regarding the intensity, duration, frequency, and

type of activity, especially for patients who are severely ill or experience orthostatic intolerance when upright.

Inactivity can result in muscle deconditioning. Providers should individualize **a threshold level of activity for each patient.** The challenge is to not overdo it and learn to adjust to less activity than before (e.g., going from easily walking a few miles to struggling to climb a flight of stairs). Some people use heart rate monitors to avoid going over the anaerobic threshold and activity monitors to avoid overexertion.

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**For more information on ME/CFS,
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